



ESTABLISHING TRUST: CREATING SUCCESSFUL ACADEMIC - COMMUNITY PARTNERSHIPS

**The Tuskegee University
National Center for Bioethics
in Research and Health Care**

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The findings and conclusions in this presentation have not been formally disseminated by the Centers for Disease Control and Prevention and should not be construed to represent any agency determination or policy.





Objectives

- Discuss the role of The Tuskegee Legacy Committee in transforming the negative legacy of the Tuskegee Study
- Discuss essential elements of a successful academic-community partnership
- Identify opportunities and challenges encountered while establishing The Bioethics Center



The Tuskegee Legacy Committee

Ms. Myrtle Adams

Macon County Health Care Authority

Ms. Patricia Clay

Macon County Health Care Authority

Dr. James A. Ferguson

School of Veterinary Medicine
Tuskegee University

Dr. John C. Fletcher, co-chair

Center for Biomedical Ethics
University of Virginia

Dr. Vanessa Northington Gamble, chair

University of Wisconsin Medical School

Dr. Lee Green

University of Alabama

Ms. Barbara Harrell

Alabama Department of Public Health

Dr. Bill Jenkins

Centers for Disease Control and Prevention

Dr. James H. Jones

University of Houston

Dr. Ralph Katz

School of Dental Medicine
University of Connecticut Health Center

Ms. Joan Echtenkamp Klein

Health Sciences Library
University of Virginia Health System

Dr. Susan Reverby

Wellesley College

Dr. Reuben Warren

Centers for Disease Control and Prevention

Mr. Anthony Winn

Minority Health Professions Foundation





Presidential Apology

“The legacy of the study at Tuskegee has reached far and deep, in ways that hurt our progress and divide our nation. We cannot be one America when a whole segment of our nation has no trust in America. An apology is the first step, and we take it with a commitment to rebuild that broken trust. We can begin by making sure there is never again another episode like this one. We need to do more to ensure that medical research practices are sound and ethical, and that researchers work more closely with communities.”

William Jefferson Clinton
May 16, 1997





Mr. Charlie Pollard



**President Clinton
&
Mr. Herman Shaw**



Mr. Herman Shaw

Tuskegee University National Center for Bioethics in Research and Health Care



DEDICATION



Marian Gray Secundy, PhD
1938-2002

Tuskegee University National Center for Bioethics in Research and Health Care

Mission

- Educate students, scholars, media, and the public about bioethical issues in public health and in the health of underserved populations
- Promote racial and ethnic diversity in the field of bioethics and in public debates about bioethical issues
- Advocate for public policies that improve the health and health care of all Americans, particularly the underserved
- Foster effective, respectful, and mutually beneficial community partnerships advocating public policies that improve the health and health care of all Americans, particularly the underserved
- Conduct research and publish scholarship on bioethics and underserved populations



Tuskegee University National Center for Bioethics in Research and Health Care Building Dedication October 20, 2006



CDC Support

- 1998 \$200,000 Planning Grant
Senior Public Health Advisor
Assigned to Tuskegee University
- 1999 \$10 million Cooperative Agreement
- 2005 \$10 million Cooperative Agreement





What is the Real Cost of the Tuskegee Study?

- Mistrust of healthcare system
- Mistrust of healthcare providers
- Mistrust of government
- Mistrust of research
- Under representation in medical trials
- Poorer medical care

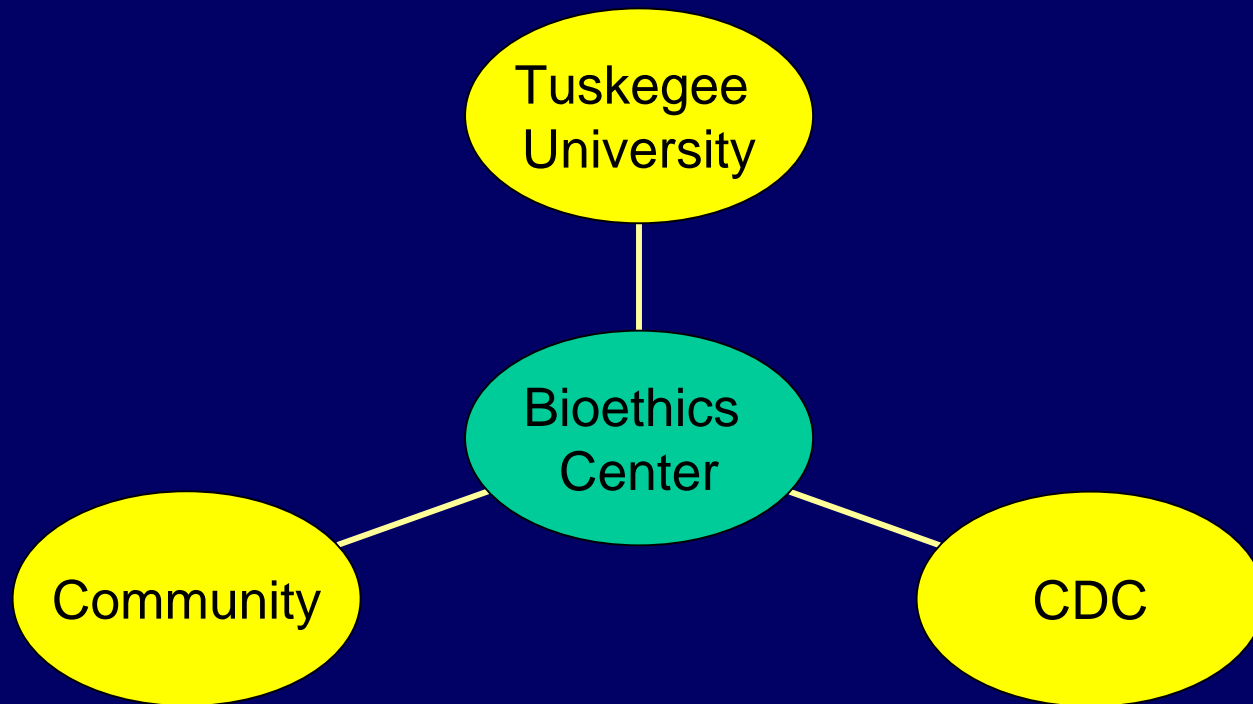


Elements of a Successful Partnership

- Agree upon mission, values, goals, and measurable outcomes
- Mutual trust, respect, genuineness and commitment
- Build upon identified strengths, assets, and areas that need improvement
- Balance power and resources among partners
- Clear, open and accessible communication



Establishing The Bioethics Center: Partnerships



Establishing The Bioethics Center: Opportunities

- **Tuskegee University**
 - University Support
 - The Tuskegee Way



Establishing The Bioethics Center: Opportunities

- **Community (local, national, bioethics)**
 - Health Care (Hospital)
 - Monument
 - Increasing university visibility while maintaining local responsibility
 - Provide content expertise and resources
 - First National Center on Bioethics
 - Train larger number of African Americans in Bioethics



Establishing The Bioethics Center: Opportunities

- CDC
 - Transform the negative legacy
 - Museum



Establishing The Bioethics Center: Challenges

- **Tuskegee University**
 - University Support
 - The Tuskegee Way



Establishing The Bioethics Center: Challenges

- **Community (local, national, bioethics)**
 - Health Care: What's in a Name?
 - Employment Opportunities
 - Addressing the financial needs of groups with similar missions
 - Select and prioritize invitations for collaboration
 - To address the needs of the nation regarding African Americans in bioethics
 - Need to partner with other well established and nationally recognized Bioethics Centers



Establishing The Bioethics Center: Challenges

- **CDC**
 - Balancing resources and technical assistance
 - Provide support for grantee during proposal development





Remaining Challenges

- Recruit and retain appropriate staff
- Improve the university infrastructure
- Maximize optimal use of available resources
- Increase the number of African Americans who pursue careers in bioethics

Conclusions

- Listen
- Respect the vantage point of each party of the partnership
- Value the opinion of others
- Reaffirm the commitment



Office of Health Disparities

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Building Trust Exercise

- Two Volunteers